

Statement of Bell Maddox Home Dialysis Patient

Hello, and thank you for inviting me to testify before this committee today. My Name is Bell Maddux and I am a home hemodialysis patient. I was diagnosed with kidney disease as a teenager and in 2008 I was fortunate to receive a living kidney donation from my father. That kidney lasted me 10 years and allowed me the gift of becoming a mom to my two amazing children. However, in 2018 I started to experience signs of kidney rejection. After 10 years of good health, with perfect labs, perfect blood pressure, I started to show elevated creatinine numbers, and my blood pressure was getting higher with each appointment. I was standing on West 4 Street in NY, on my way to work, when my nephrologist called from her vacation and yelled through a bad connection that I needed to get to the emergency room immediately.

From that point, my health plummeted. I was unable to eat. My weight went down to a number I hadn't seen since I was twelve years old. For four months, I struggled making my daily commute from the Hudson Valley to work in New York City. Driving to the train station, then the train to the subway, by the time I got to my last subway transfer, I couldn't take more than a few steps at a time without stopping to rest on a support beam. At work, I found it difficult to stay in my chair all day, and often had to retreat to a back room where I could do my work laying on the floor.

Dialysis had been a long-standing fear of mine, but now it was time to start. One week after I had the procedure to insert the tunnel catheter into my jugular, I sat in my car outside of the dialysis clinic, struggling to breath. But I went in and began my life as a dialysis patient. Once I started, and felt the effects, I realized how much I needed it to continue functioning in my day-to-day.

Three days a week, I sat in a chair for three hours straight while the dialysis machine did 17% of the work that my kidneys would have been doing continuously. The clinic was five minutes away, but my life quickly became dominated by getting to and doing treatment. Every Tuesday, Thursday, and Saturday, I had to arrive at around 1:30 to prepare for a 2pm chair time. By the time I left, it was 5:30. Saturdays with my family were completely gone, and things like birthday parties and soccer matches, I just had to miss. I am thankful that my company allowed me to work from home on those two days, so I could bring my laptop with me to the clinic to continue working during my chair time. I wanted to maintain my 15-year career as a digital project manager. I also wanted to be valuable to my team, but participating in client calls and team meetings was impossible with the machine alarms constantly beeping and patients in distress, or just getting loud in frustration. With just one nurse and two technicians, I also felt I had a front row seat to the workplace politics and constant changing requirements that had little to do with patient care that bogged down the staff. It was a difficult place to be in for so many reasons. Many of the other patients had mobility issues and relied on medical transport services to bring them from their home, sometimes 45 minutes away. One very kind man told me that he did nothing else in his life, except go to dialysis and wait to go to dialysis. Urged by one of the nurses, I decided to change to another center that was further away.

And this one was much better, even though there was still background noise during work calls, the staff did what they could to accommodate me. But then things got more complicated. I was notified by the clinic's financial coordinator that my insurance company was not paying for my treatments. Apparently while everything else was covered, this particular location was out of network. The insurance company sent me to a location and a new doctor that was twice the distance away. It was at this clinic, where I experienced a painful infiltration for the first time. It was at this clinic that I started experiencing muscle weakness and had a hard time walking again. My doctor discovered that the staff inexplicably stopped administering the medication that sustained my hemoglobin levels. Of course, this was in 2020 and Covid was sweeping through crowded clinics, and I was hearing about dialysis patients like me catching it in the clinic and dying.

I was often asked why I was not automatically choosing home dialysis, and I didn't know much about it, but being already overwhelmed with two small children and failing health, I was reluctant to take on the added responsibility. But after this series of terrible experiences, I felt that there was no choice, I had to get out of that clinic. My doctor explained that doing more frequent treatments would be easier on my body, and I would get some relief from the physical symptoms I was experiencing. I went to the floor nurse and asked for an appointment with the home training nurse. They all seemed excited, and gave me some folders, and papers to read, and then I heard nothing for weeks. Follow up calls from me and from my doctor, got no response, and finally the scheduled appointment was made during the nurse's vacation. I was trying to coordinate a move to a larger home in Pennsylvania but was getting nowhere with making this transition. My doctor was equally frustrated and handed me the private cell phone number of a home dialysis nurse at another center.

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My new nurse took care of everything, including training me how to cannulate myself, how to rotate needle positions to avoid damaging my access, how to draw and process my own blood for labs, and how to administer my own medication. After the first week of training, and doing consecutive treatments, my health improved exponentially. My energy was up, my symptoms eased, and my diet and fluid struggles disappeared. I even got comments on the improvement in the pallor of my skin.

Today I do my dialysis treatments at home. What that means is that my entire day is free, every day. After I make dinner, I take ten minutes to set up the machine, and lay out my supplies. Then I do bath time and bedtime stories with my kids, maybe squeeze in a quick tidy-up before I take my vitals and settle in with my electric blanket and a movie. Now, I can choose to do work during treatment, or I can choose to do treatment after work. When I'm done, I can be pretty wiped out, but instead of getting behind the wheel of my car, I take three steps and get in my bed. It also means that my free time is no longer devoted to preparing for or recovering from treatment. Since my body is no longer able to process liquids, the accumulation of fluid in my body, around my lungs and heart, between treatments had been my biggest challenge. Having enough discipline to drink less than 30oz over two days, while my body was screaming to have a

tall, dripping glass of ice water, is the closest I ever want to come to being in Hell again. Now, if I'm thirsty, I can have juice, or water, or root beer, and if I ever overdo it, I can do an extra treatment to remove the excess fluid.

My initial perception of being a home-dialysis patient was not wrong. It is a lot of work, especially having opted to be a solo patient, which means that I do everything myself without the help of a caregiver. Sort of like driving a car, it's definitely not without risks and it's not for everyone. But the benefits are such that I think every person on dialysis should be empowered with the choice and armed with support and sufficient information to make the right choice for themselves. My son doesn't remember me ever being in clinic, but my daughter remembers wishing I didn't have to go all the time. They both prefer to have me at home. Having that choice is second only to having a working kidney.